Patients, providers, and systems

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CHAPTER 9

Discussion and conclusion

The rapid increase in the prevalence of chronic conditions in sub-Saharan Africa requires a better understanding of how health systems within this context are organised and how they respond to the growing needs for long-term care. The main aim of this thesis was to contribute to a better understanding of local models for chronic care and self-management support within the African context, as well as gain insights into their performance. A rural district in Malawi constituted the main case example. The central question guiding this thesis was as follows:

What local innovations and practices exist for the self-management of patients living with chronic conditions, and how do these contribute to patient outcomes and to the delivery of responsive chronic care at primary care level in Malawi?

The relevance of addressing this question was two-fold: first, to understand and contextualize the challenges and opportunities within local health systems in resource-limited settings, as they strive to reorient towards delivering responsive chronic care at scale, and especially in primary care settings; and, second, to generate evidence of the local innovations and practices of self-management, considered a critical principle in chronic disease management. Chapters 4 to 8, which constitute the thesis results, were framed to address three related sub-questions. This section summarises the main findings under each sub-question. We conclude the chapter with a presentation of the overall implication of our findings and recommendations for research, policy, and practice. We further reflect on some theoretical and methodological consideration of our research.

ANSWERING THESIS SUB-QUESTIONS

1. *How is chronic disease self-management conceptualised by patients and providers of care, and what factors contribute to variations in experiences and practices in resource-limited settings?*

In Chapter 4, we provided detailed accounts of patients lived experiences of how they managed various chronic conditions and the self-management strategies they adopted. Patients viewed self-management as the continuous process of managing symptoms and illness episodes. Self-management practices involved medical management and ensuring that patients adhered to medical advice, by using reminders such as putting medication near bed, scheduling drug intake after meals or using day/nightlight time as reminders. Maintaining a healthy lifestyle for patients in this context largely overlapped with daily routines of physical activity, such as walking and cycling long distances, and a physical/labour-intensive occupation such as farm work. We found that patient adaptiveness and resilience to respond to changes arising from their condition was an individualised process, and influenced by factors within and outside their environment. Overall, patients' demonstrated

capacity to manage their chronic conditions despite the myriad of challenges encountered. These challenges are summarised in the following sections.

Patient health status and physiological state

In Chapter 4, most patients reported experiencing pain and fatigue, which limited their capacity to engage in daily/social roles, while those with mobility challenges felt incapacitated, in for instance personal care, and thus relied heavily on family caregivers. In Chapter 6, our survey indicated patient self-efficacy (the confidence to manage chronic condition) decreased with an increase in illness intrusiveness and presence of symptoms such as pain, fatigue, emotional distress, and a decrease in patient's general health status. Furthermore, the daily living challenges compounded the patient's capacity to self-manage. Corbin and Strauss [1], have emphasized the need to take cognisance of patients' multiple needs (including non-medical needs) and their illness trajectory, and how these impact their wellbeing. For instance, if patients perceive daily struggles (e.g. source of income and inability to secure adequate food) as more important than treatment adherence, then it is important to support patients in their special circumstances. In addition, support should also take into account that care needs may differ due to other factors such as gender and age, and would require a more responsive approach. However, in most cases healthcare professionals may not be attuned to a patient's social environment, or have an ability to address the conditions within a patient's environment that negatively influence his/her health status (also discussed in Chapter 2), and thus fail to provide optimal support during patient-provider interactions.

Care seeking behaviour and health system factors

The inconsistency in the availability of medication impacted patient's general health and ability to manage condition-related complications. Patients with epilepsy, diabetes, and hypertension, were more likely to miss taking their medication compared to HIV patients (Chapter 4). This variation was attributed to chronic stock-out of essential medicines especially in public primary care facilities, which the majority of patients relied on for their medical needs. To navigate these barriers, patients resorted to rationing drugs for future illness episodes, taking medication only when presented with symptoms, or opting to use traditional medicine; yet these alternative strategies could put patients further at risk. Other key factors significantly influencing care-seeking behaviour were the proximity to healthcare services, geographical, and financial access barriers. Patients living in far-flung areas were more disadvantaged in accessing specialised and referral care due to poor transport network and weak ambulatory care services. User-fees charged in private healthcare facilities deterred patients from utilising these services, and patients rather opted to seek care in public facilities, where services were free at point of care. Despite the existence of a universal 'free public healthcare' policy in Malawi [2], the absence of financial protection mechanism in form of a national health insurance scheme, appeared to disproportionately affect the poor and those not in formal employment [3]. The above

challenges have been widely documented as common barriers to healthcare access in other African settings as well [4, 5], and are more pronounced among NCD and multi-morbid patients [6, 7]. More importantly, the absence of financial protection mechanisms from catastrophic health expenditures disproportionally affects the poor and rural households [8-10]. This evidence highlights the strong urgency in reducing such disparities, as experienced by patients, and finding appropriate ways to expand universal and equitable access to health services for disadvantaged populations.

Social relations

Patients' conditions impacted on the relationships they had with others (Chapter 4), and in turn influenced their perceived self-efficacy (Chapter 6). In Chapter 4, patients who reported they were in steady relationships praised the care and support from their partners. These observations corroborate with the findings in Chapter 6, where the odds for self-efficacy improvement were higher for married patients than those not married (i.e. single, widowed or separated/divorced). Elderly patients reported that having a chronic condition led to less affection from their spouses and feelings of abandonment. Among HIV patients, revealing their disease status to partners led to separation and reduced chances of entering into new relationships or marriage. Patients also experienced emotional distress/stress due to their condition and stressors within their environment. These manifested in the form of differential treatment, being isolated from communal and social activities, or verbal insults, commonly reported by HIV, epilepsy, stroke, and cancer patients. To address these stressors, patients adapted various strategies, which resonated with the adaptation mechanisms described in the self-efficacy theory [11, 12]. For instance, withdrawing or isolating themselves from people or situations contributing to these negative experiences (self-regulation); reporting incidents to the local authority and healthcare providers; seeking solace from their significant others; and sharing and learning from experiences of peers in support groups (vicarious learning) were common strategies among HIV patients. HIV patients' strategies to prevent public knowledge of their disease status included accessing care in health facilities away from their neighbourhood, and interchanging between health passports for HIV and non-HIV consultations in order to conceal their disease status. These different coping strategies found among patients in our context are similar to those observed in other African studies, where chronically-ill patients were seen to enact a sense of normalcy amidst the stigma and discrimination events they encountered [13-15].

CARE PROVIDERS CONCEPTUALISATION OF SELF-MANAGEMENT AND SUPPORT PROVIDED

At the household level, patients mostly relied on immediate family members and relatives living within same households for support. Family caregivers perceived their responsibility to support patient self-management included providing

emotional support, offering financial assistance to cater for their medical needs, assisting patients in adhering to treatment and dietary advice. However, the frequent illness episodes and care demands weighed on family caregivers, which resulted to infrequent or discontinued support due to resource constraints, engagement in other responsibilities, and feeling overwhelmed as illustrated in Chapter 4. This phenomenon resonates with findings reported in two Botswana studies [16, 17], on the burden of family caregivers supporting home-based care in a context of a high HIV epidemic. These studies highlight the gendered dynamics of caregiving (predominantly by older females) and the material deprivation, which makes caregiving very challenging. Therefore, there is a strong need to improve the conditions under which care is given (either through financial, social or psychological support systems) to alleviate, where possible, some of these stressors on caregivers, and for the benefit of the patients served in the home situation.

In Chapter 5, healthcare professionals' perceptions and conceptualisation of self-management appeared to align with principles articulated in the international literature on chronic disease management [18, 19]. For instance, an awareness of patient engagement in care and their responsibilities; the value of an extended care team, which also includes community caregivers such as community health volunteers (CHVs); and acknowledgement of the active role of family caregivers. Healthcare professionals in rural Malawi recognised the importance of patient empowerment and providing the requisite support and resources for patients' self-management. They understood their role entailed transferring knowledge through patient education to help patients improve on their disease knowledge, symptom monitoring and lifestyle management (diet and exercise), and prepare patients for their medical roles (e.g. adhering to medication and clinic appointments). However, the application of these principles and their promotion in daily practice faced serious challenges. For example, patient education was mostly unstructured and done in crowded settings by non-professional providers (health surveillance assistants), which minimised opportunities for patients to actively engage in care decisions and expand their health literacy. Moreover, patients surveyed identified healthcare professionals as their main source for deriving health-related knowledge, yet they lacked sufficient training in chronic disease management. In a South African study, Maimella et al [20], similarly came across healthcare professionals who, while acknowledging that clinic consultations provided them with the opportunities for information exchange and promotion of self-management practices, they lacked the resources such as quality equipment and promotional materials to do so. In addition, the training curricular for healthcare providers within sub-Saharan Africa could draw more extensively on the principles promoted in family medicine, with particular emphasis on the biopsychosocial approach to patient care and community-orientation [21, 22]. To minimise the missed opportunities where patients leave clinic settings with inadequate information, the active engagement of family caregivers accompanying patients during consultations provide important pathways to strengthen agency

in care and capacity to perform close home-monitoring. The active involvement of other community caregiver groups such as volunteers in community-home based care (CHBC) programmes and peer-support groups were identified as important information dissemination sources. This asserts the need for activating their role and empowering these networks with appropriate knowledge to impart to the patients they serve.

Community/Faith-Based Organisations (CBO/FBOs) offered care and support to patients enrolled in their CHBC programmes. CHBC providers understood that patients with chronic conditions had multiple needs and that their responsibility as community caregivers was to help alleviate some of the challenges (particularly psychosocial) patients faced in their home environment, which affected their self-management capacities. For instance, the economic hardship and poverty faced in this rural setting raised a demand for livelihood support programmes, to which the community caregivers responded by means of referral. The majority of CHBC programmes emerged in response to the impact of HIV/AIDS on the community, and for the programmes we studied, the programmes now also included patients with conditions other than HIV. CHBC providers perceived offering psychosocial support and counselling helped patients and their families deal with the emotional toil of managing a chronic condition. The caregiving practices by the CHBC providers we studied, align with the recommended guidelines of delivering home-based care as stipulated in Malawi's national guidelines [23], and resonate with other international guidelines, such as the WHO community home-based care framework [24]. During home visits, CHBC providers played a navigation role by offering patients some form of health education and referred those needing medical attention for facility care. However, a challenge expressed by CHBC providers was the inability to meet patients' expectations and fulfil their material needs, such as, provision of food rations, or support to procure medical supplies, as commonly identified needs by patients.

2. *What models of care and innovations exist within community and primary care settings to support delivery of chronic care, and what is their potential impact on patient self-management outcomes in resource-limited settings?*

Under this sub-question, we provide evidence on the practice of chronic care and self-management support initiatives in existence in facility and community settings in rural Malawi (Chapter 5). By examining existing models/frameworks of chronic disease management such as Wagner's Chronic Care Management and the WHO ICCC framework [18, 19], discussed in Chapter 2, we explore how the principles advocated in these models feature within the studied initiatives, challenges faced, and potential opportunities of leveraging their relevance in chronic care in Malawi, and other resource-limited sSA settings. More importantly, we examine how these support initiatives impact on self-management outcomes (Chapter 6).

Within the Malawian landscape, the evolution of CHBC from a predominant HIV focus to an expanded model that incorporates other chronic conditions signifies the country's progress and commitment towards universality in provision of community-based chronic care [25-28]. This is supported by the presence of a national framework which standardises the provision of CHBC as a component of health service delivery in the country [23]. Provision of home-based care takes recognition that most of the caregiving tasks occur within patient's homes, and care is provided by an extended team including patients themselves, family caregivers, community-based caregivers, and supported by healthcare professionals [23, 24]. The WHO ICCC framework [19], places emphasis on the need to engage community-based structures to support with the mobilisation and coordination of resources, and provide complementary services. Our study in rural Malawi showed this practice was promoted through the provision of CHBC by volunteers in community/faith-based organisations (CBO/FBOs), situated within communities where patients reside. CHBC providers' unique attribute is that they understand patient's social realities, which may promote or limit their self-management capacity, and are better placed to comprehend patients' needs as compared to facility-based providers. The self-management support offered by CHBC providers in our setting included: health education and counselling; provision of physical care; assisting with domestic chores; psychosocial support through emotional and spiritual encouragement; and promoting continuity of care through referral of sick patients and close home monitoring.

The CHBC programmes we studied showed that, even at a minimal level, there are benefits that patients derive from exposure and interaction with CHBC activities. Chapter 6 delved into the contribution of CHBC on selected self-management outcomes. We reported a decline in patient-reported symptoms (pain and fatigue) over 12-month of follow-up after enrolment in CHBC programmes and a decline in illness intrusiveness, which signifies the extent to which conditions affect patient's daily functioning. Patients who were regularly visited (at least three times a month) by CHBC providers had better self-efficacy and the odds for improvement were higher after six months of enrolment in CHBC programme. The regularity of CHBC contact also influenced patients' perceptions of CHBC support. That is, in programmes that maintained regular monthly visits, patients were more satisfied with the programme. To the best of our knowledge, our study is among the few to focus on the CHBC's contribution on self-management outcomes for a heterogeneous group of chronic patients. Other studies within the region have demonstrated the benefits of CHBC in, for instance, improving HIV-patient retention on antiretroviral therapy, increasing community screening and health promotion services, and allowing for the decentralisation of HIV services closer to patients home setting [29-32].

Several challenges posed a threat to the contribution of CHBC programmes in chronic care within our study context, further elaborated under sub-question 3. These programmes largely operate on voluntary-basis with no external funding support,

which they once attracted under national HIV/AIDS programmes. The declining trend of global funding to support national HIV/AIDS programmes [25, 32], and the reliance of these funds to also support grassroot activities including CHBC programmes, has affected the state of their contribution to healthcare. To illustrate, the level of CHBC providers training, in most instances, was a one-off basic training and their technical knowledge on chronic disease management was insufficient. This was compounded by the absence of a training curriculum that had an expanded focus on care for other major non-communicable diseases [23]. The above structural and resource challenges were a major setback to replicating this model to a non-HIV patient population and engineering the scale-up of this initiative.

Peer-driven initiatives such as patient support groups and expert patients were present at the community level, to serve patients with chronic conditions. These models of care originated from HIV/AIDS programmes, as innovations to increase patient access to care and facilitate the continuity of care [33-35]. Their focus has mainly been on health promotion, home tracing of patients lost to care, psychosocial support, and modelling positive health behaviour. Evidence from the region indicates that peer-driven initiatives have contributed to improved adherence to treatment and HIV care, and are a feasible approach to decentralise care and support to the community level [29, 31, 34, 36]. In Chapter 5, both patients who were in and those not in support groups acknowledged the prominent role of patient support groups in self-management. They perceived the regularity of meetings with peers provided an avenue to reinforce health advice and instructions, promote collective problem-solving which contributed to a sense of collective efficacy, and offer patients an enabling environment/'safe space' to deal with stressors. A major limitation was that these initiatives were disease-focused and catered to HIV patients (largely due to the well-resourced HIV/AIDS programme), whilst non-HIV patients expressed a strong desire for the formation of patient support groups for a heterogeneous chronic patient population. In recognition of the potential for peer-driven initiatives in addressing patients' unmet needs, there may be some design features which could possibly limit their utility. For instance, as we observed in our context, membership requirement (ability to pay membership fee, entry of new members is condition-bound), leadership and group dynamics that may affect group functioning/social cohesion, and patient-preferences (desire or lack thereof to be identified or participate in groups) [37]. There is emerging evidence from other sSA settings on the benefits of experimenting with mixed patient groups e.g. medical adherence clubs for HIV and NCD patients reported in South Africa and Kenya [38, 39]. However, caution is needed to ensure sensitive issues such as disclosure and stigma are addressed with the formation of mixed patient support groups [39]. In Malawi, opportunities lie in activating the role of national patient organisation networks such as NAPHAM (National Association of People Living with Malawi), who support the network of HIV support groups and promote HIV/AIDS advocacy. There is potential to pursue within these organisations the expansion of the scope of their activities from a principal HIV focus to include

health education and awareness of other chronic diseases, provision of care and support to multimorbid patients, and capacity strengthening of community actors on these areas.

At the facility-level, there were efforts to form a community-oriented primary healthcare team. The Health Surveillance Assistants (HSAs), discussed in Chapter 7, are a state-paid community health worker cadre in Malawi, provided a link between facility-based and community health services, and were tasked with the supervision of community-based structures [40, 41]. Similar to other community health workers in the region, such as Ethiopia's health extension workers [42], Malawi's HSAs became a fully professionalised cadre in 1998, to address the country's health workforce shortage and deliver a broad range of community-based interventions [40], including supporting NCD care [43]. Within our setting, HSAs unique position allowed for patient home monitoring and initiating early referral to care. However, there were concerns of the poor linkages between them and other community-based structures e.g. CBO/FBOs, which diminished their active presence and provision of supportive supervision to these networks of community partners.

3. *How are local health systems and processes currently structured, and what adaptations may be required to enable responsive quality care for patients with different chronic conditions in resource-limited settings?*

In this section, we provide evidence of how chronic care in Malawi is currently organised, especially at the community and primary care levels. In Chapter 7, the need for coordinated chronic care was explored further and we utilised integrated care frameworks to interrogate the state of evidence [44]. We also reflected on the country's policy directions, by particularly analysing the recently launched National Community Health strategy [45], to help leverage the scale-up of responsive quality care for chronic conditions in Malawi under Chapters 7 and 8.

Malawi's National Health Sector Strategy provides guidance as to how essential health services are organised and delivered at the different tiers of the health system [2]. Similar to many other African health systems, Malawi's health programmes fall under different departments/directorates of health, under which intervention packages are categorised e.g. HIV/AIDS, NCDs, and community health [2]. However, this continued separationist nature of health programmes and financing initiated at the national level, institutionalises fragmentation of services, especially at the primary level, and constrains patients' access to a comprehensive continuum of services that is critical in chronic care [46]. In our study, this manifested in a poor availability of public primary care services for NCDs, whilst HIV treatment services at this level tended to be well-resourced, drawing on multiple financing initiatives (both domestic and external) and a strong political commitment to prioritising the HIV/AIDS programme on the national health agenda [47]. NCD programmes on the contrary received a smaller

funding allocation (below 10% of the national health budget), and the programmatic structure at national level was still underdeveloped by 2015–2016; the time of this study [48]. This affected service provision, occasioned by chronic stock-outs of essential medicines and diagnostics in public primary care facilities. The progress with integrating NCD services within primary care settings in the sSA region has been mixed. Reasons for this are largely attributed to deficiencies in the health system infrastructure and a poor policy uptake of the WHO recommended package of essential NCD interventions [49, 50]. In order to address these resource and structural barriers, several proposals have been made since, and include improvements in the availability of essential equipment, supplies and medicines; setting up functional referral systems; use of monitoring tools; and training health service providers [49, 51, 52]. The future of NCD programming may change, as a result of a growing international attention and rallying towards increasing financing for NCDs, and improving service delivery structures through integration, and the emergence of vibrant advocacy groups such as the NCD Alliance.

There have been attempts to integrate services at point of care as prescribed by national policies, and by using the network of community-based providers and HSAs to expand services at community level. Malawi is making progress towards aligning the organisation of health services with the "Health for All" agenda. In 2017, the launching of the National Community Health Strategy aimed at further decentralisation of services at community level, expanding the scope and coverage of essential services, and the harmonisation of community actors and structures to offer services in a more coordinated fashion [45]. While the ambition of the strategy is to minimise health inequities in service provision and access by year 2022 [45], there are notable gaps in the current policy requiring further streamlining. One, is the need for equal access to community-based resources for both HIV and NCD patients. The current set-up of the community essential health package is minimalistic for NCD services (e.g. provision of psychosocial care), and may require modification to include multi-disease screening and diagnostic services, and to ensure that essential medicines for NCDs are constantly available.

The important role of community health volunteers (CHVs) and volunteer-led programmes within community health systems is recognised as a driving force behind the primary healthcare agenda, and pathway to delivering universal healthcare among underserved communities [53-55]. The operationalisation of this agenda in Malawi through its National Community Health Strategy and other key policy documents builds in part on an expansion and reinvigoration of volunteer-led programmes. However, as discussed in Chapter 8, the collaborative working relation between state-paid community-based health workers (HSAs) and community health volunteers (CHVs), who are expected to operate on a team-based approach has not fully crystallised to take effect. A loose description of CHVs, their roles, modalities of engagement and CHBC programmes absorption under the strategy requires further

thought and positioning by the government. Based on our study findings, we see opportunities of co-opting trained CHVs from the existing network of volunteer-led programmes into community health teams (CHTs), as well as task-shifting health promotion and home tracing activities to CHBC programmes which are embedded in communities, leaving facility-based HSAs to support outreach activities and other specialised tasks under the community-level EHP interventions. However, the decision to expand and reinvigorate the role of CHVs in community-based healthcare cannot be taken without careful consideration of a fair and appropriate form of compensation to CHVs, and the structure they represent. The ongoing debate on an appropriate incentive structure for volunteers in community-based programmes, as well as the repercussions for failing to make these provisions have been widely documented, [53, 56-58]. In a multicountry African study among salaried and volunteer community-based health workers, Ormel et al [58], found that while financial incentives were appreciated, they also argued that in order to sustain the performance and motivation to volunteer, these monetary incentives need to be complemented with other incentive types and job-enablers. For instance, provision of training opportunities, work supplies, and regular supportive supervision to enhance the delivery of quality care. They further assert that in the absence of such, there is no valid mechanism for health systems to hold volunteers accountable for their performance [58]. On the other hand, providing remuneration risks volunteers paying more attention to the health sector rather than prioritising and being accountable to their communities [58]. Other studies have also cautioned against irregular payments, paying lower than expected amounts, and failing to consider expectations such as career development and further training, which may serve as disincentives and affect performance [57, 59, 60].

While it appears there is strong recognition for providing some form of incentive to volunteers, the outstanding issue that remains is how countries, which heavily depend on a community-based health workforce, should make investments sustainable, and what financing options should be pursued. To illustrate, implementing Malawi's community health strategy for 5 years (2017–2022) has been valued at US $407 million, of which the proportion allocated for paid community-health worker cadre salaries is 30%. Expenditure is expected to be shouldered by central and district governments [45]. As it currently stands, there is no budget line for CHVs financial remuneration, except for procurement of CHVs work supplies listed in the community package of interventions costed at US$ 5,985. Furthermore, the provision of non-monetary incentives such as bicycles has been allocated to prioritised community structures (e.g. village health committees) but excludes volunteers outside these structures (e.g. CHBC volunteers). This oversight or inability to be fully inclusive not only affects the full implementation of Malawi's strategy but also threatens the long-term existence of volunteer-led community programmes. Taylor et al [60], explored different financing options for national community health worker programmes in sSA, and recommended the following to countries with low affordability; one, to

consider a reallocation of funds within the health services or strive for efficiency savings. Second, to reduce or limit the scope of roles for this workforce to key tasks/ disease areas as a cost-reduction strategy. While plausible as a short-term strategy, it may prove impractical in contexts like ours where one requires a skilled generalist rather than a specialist community workforce. The long-term option for governments, dependent on central budgets, is to increase the total healthcare budget, following an expansion of the tax-base and capacity to generate local revenue. The above proposals, closely tie in with recent recommendations from the WHO guidelines for optimizing community health worker programmes with a strong emphasis on the need for innovative financing, strategies which are country and context-specific, as well as the provision of job enablers and supportive supervision are instrumental [56, 61].

The critical importance of a coordinated approach to the organisation and delivery of chronic care was discussed in Chapter 7, in spite of the continued presence of vertical programming for health and as anchored tightly in both government and funding agencies' systems and procedures. We observed a shift, albeit incremental, towards integrated service delivery in policy and in practice. In our context, the integrated approaches pursued was largely for instrumental purposes, characterised by attempts to coordinate activities of different programmes at point of care. Evidence from other parts of the country and from other sSA settings demonstrates the use of HIV service platforms to leverage care for other chronic NCDs [62-65]. However, eminent challenges exist such as the absence of a multi-professional health workforce and the poor state of general primary care services, which makes integration a complex endeavour. Integration is deemed to contribute to the delivery of efficient services that are more responsive to patients' needs, improve health outcomes, and encourage cost-savings in the long-term [44, 66]. However, integrated health services are neither a cheap nor a straightforward option, as they require amalgamating different service structures (both public and private) and a coordinating mechanism that can pull together the different key actors and funding streams [66, 67]. While it appears that these functions remained rather centralised within National level structures, in devolved health systems like Malawi, we observed the district level structures play a central role in further steering towards integration through enacting a leadership role and synergising the activities of public and private sector providers in health. To fulfil these roles more effectively, there is a need for strong governance structures at district level, underpinned by provisions of technical support from the National level, collaborative frameworks between multiple providers and institutions delivering health services, the active involvement of social service sectors, and the financial support to oversee implementation of integrative strategies in districts.

OVERALL CONCLUSION AND CONTRIBUTION TO POLICY AND PRACTICE

This thesis contributes evidence on how chronic disease management should be conceptualised in resource-limited sSA settings, and through this understanding it paves the way for better planning and prioritisation of resources based on identified needs. First, the evidence confirms that the drivers and determinants of health are broad-based and surpass the individual, behavioural, and biological factors, which are often cited in the NCD literature [68]. A recent Malawian report established that the prominent determinants in the development of chronic diseases in Malawi are linked to infectious diseases and environmental factors, driven by inequities in wealth and socio-economic status [69]. Enabling care providers to tackle chronic conditions more effectively will require a shift away from the traditional biomedical model to a more patient-centred approach to care; which considers interpersonal aspects of health care and involves patients, caregivers and health providers in making decisions and evaluating the quality of care; and strengthening a therapeutic relationship long-term [70]. This also requires an acknowledgement that patients should be encouraged to play an active role in care, empowered by the requisite information and links to resources to support their self-management practices.

The models of volunteer-led CHBC programmes and peer-driven initiatives emerged as locally relevant and available community resources towards the self-management of patients with chronic conditions living in a rural district of Malawi. Provision of support, particularly in terms of psychosocial support, and opportunities provided for learning and gaining of practical skills to deal with chronic conditions were strongly valued by patients and their family caregivers. The stark differences observed between HIV and non-HIV patients in accessing these forms of support and health services in general, pointed to a need to remodel local initiatives and strengthen health service provision to become more inclusive. Furthermore, Malawi's recent reforms in the area of community health will require an evaluation at mid-term to assess the extent to which implementation is on course. The complexities around sustainable financing, human resource planning, and incentive structure for paid and unpaid community health workforce are pertinent issues for consideration in implementing such policies. The evidence presented here and from elsewhere in the region, underscores the need for multi-sectoral planning and collaboration, innovation in financing, and pragmatic restructuring of the health workforce. At governance level, further negotiations will be necessary to bring more alignment between donor-funded health programmes and national health priorities, and to guide resource allocation towards emerging health problems and prevent their exacerbation.

Finally, while a coordinated approach to chronic care is highly desirable, health systems are complex by design and functionality. For integrated systems to be achieved in contexts where verticalization has long been the norm, a reconfiguration

of various health system inputs may well require a lengthier and more adaptive process, under the strong leadership of the Health Ministry. For Malawi, especially focusing on the primary care level, it will require experimenting with a combination of approaches such as multi-functional community outreach services with strong referral network with primary care facilities, whilst further strengthening the health system functions such as an improved supply chain system.

RESEARCH STRENGTHS, LIMITATIONS, AND VALIDITY

The overall research utilised a case-study design, with a single case unit (a rural district) and concurrent mixed methods approach to data collection. This approach enabled us to investigate the study topic with a great level of depth, applying a range of robust data collection methods (surveys, interviews, group discussion, structured observations, and document analysis), followed by triangulation and comparative analysis. However, this choice of study design limits the extent to which findings can be extrapolated to other parts within and beyond Malawi. To address this limitation, we compared our findings with the literature on community models from other settings, particularly those within sSA that share similar characteristics. We acknowledge that a case study with multiple case-units, preferably multi-country case examples, may have been more scientifically robust, yet would have required substantially more resources and time to implement. Using existing frameworks such as Valentijn's integrated care framework [44], enabled us interrogate the extent to which integration occurs in primary care settings. However, our analysis did not assess other dimensions of integration (normative and functional) as described in the framework, due to limitations within our dataset.

The choice of programmes studied (i.e. CHBC programmes that had concluded a pilot intervention two years prior to our survey evaluation) could have had an impact on outcomes of interest (i.e. whether exposure to CHBC support impacts on patient self-management outcomes). On the other hand, including programmes that all participated in the same intervention also allowed us to reflect on the sustainability of donor-initiated programmes, and our outsider status allowed us to do this independently. A methodological limitation which was carefully discussed and weighed by the team during the design phase of the study and thereafter was the use of a one-group pre and post-test survey without a comparison group. This choice affected the capacity to draw causal inferences, and may have rendered our analysis prone to misspecifications in examining the relationship between variables. We partly countered this by analysing some of the outcome variables (e.g. self-efficacy) at single-time points in order to explore relationships more closely. The relatively long period of qualitative and quantitative data collection (12 months) within the same study population enabled the research team to build and maintain trust with respondents, and the different data collection cycles presented an important opportunity to

investigate emerging findings and adapt tools where deemed necessary. Another strength was the focus of our research aimed at addressing policy relevant questions (e.g. implementation of a national community health strategy), facilitated by working closely and collaborating with local stakeholders such as district health managers.

Finally, given the outsider status of the research team, we openly discussed and documented, within internal feedback meetings, how our roles and background could influence the interpretation of our research findings. Working in close consultation with local collaborators and the district health personnel, provided a sound counterbalance, and facilitated the management of practical issues related to the research implementation.

SUGGESTIONS FOR FUTURE RESEARCH

The growing number of multimorbid chronic patients worldwide presents a key global research challenge. Given the large diversification of health system contexts and patient needs across the globe, a focus on cross-cutting thematic areas such as human resource planning for integrated systems, care and support systems for diverse patient groups, and generating population-level studies on the burden of multimorbidity could be valuable for guiding national and regional research agendas. Task-shifting reforms for integrated chronic care are important and in the sSA setting, the direction is towards community-based health worker cadres and volunteers. This should be complemented by a performant public-oriented healthcare delivery system, with strong linkages to the various health service structures. An efficient delivery system closely relies on a functional clinical information system. A challenge we encountered was that health information systems and reporting were largely programme specific, with the NCD programme still in a developmental stage. Real-time data will be critical in providing true estimates of disease burdens and inform resource-planning exercises. Further empirical research will be needed to investigate and expand the current body of evidence on self-management support interventions and to test localised equivalents of the chronic disease self-management programme curricula for use by paraprofessionals and CHBC volunteers, and the application of decision support tools for NCD management at primary level, including testing the feasibility of delivering these resources in mobile/electronic platforms.

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